

of the remaining 16 patients, 75% returned to normal oral intake (median 260 days). Of those that had full conditioning treatment (n=31), 22 returned to normal oral intake with a mean of 187 days. GvHD and duration of PN were correlated with return to oral intake. Gender, pre-HSCT oral intake and infections were not associated with oral intake.

Conclusion: Oral intake in young children post HSCT is inadequate. PN is required during the period of maximal gut toxicity. The majority of these children are NG fed for large periods of time prior to resumption of oral intake, and not all children return to their normal dietary pattern.

## Development and support

### N1107

#### **An exploratory and comparative study between patients undergoing HSCT treatment, patients with mean of 3.2 years after HSCT, and disease-free people**

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Introduction: Haematopoietic Stem Cell Transplant (HSCT), known as Bone Marrow Transplant (BMT), is a life-saving therapy for many patients with malignant and non-malignant disease, who has no chance of cure a few years ago. Despite of this, HSCT, is associated with significant risks of morbidity and mortality and it's always seed as highly stressful even under the best circumstances and good cares.

The HSCT affect directly the patients Quality of Life (QoL). For this study, QoL was based on the QoL model for BMT Survivors developed by Ferrell and Grant (1992) that depicts the QoL domains of physical well-being, psychological well-being, social concerns and spiritual well-being.

Methods: We are sure that to improve current nursing practice we need to deeply know HSCT patients QoL. We made an exploratory and comparative study between patients undergoing HSCT treatment (n=30), patients with mean of 3.2 years after HSCT, (n=30) and disease free people (n=30) to better know their QoL. We matched the three groups regard to age and sex.

After obtained the informed consent, we ask all the participants to fill a questionnaire, assessing some biological and socio professional aspects. We also used a BMT Survivors scale, with a high alpha de Cronbach ( $>.89$ ), a Mental Health Inventory Scale -5, and a Positive and Negative Affect scale. Both disease groups fill the full questionnaire and the free disease group fills a questionnaire without specifics aspects for BMT patients.

Results: Results found no statistical differences between the three groups. We only found differences between averages: for a maxim of 10 points (better QoL) we found 6.4 for the inpatient group, 6.1 for the outpatients group and 7 the free disease group. QoL is explained for different domains in different groups. While spiritual domain score more in the diseases groups, the physical domain scored better in the disease free group.

Kneeing the most important QoL domains for each group could be a clue to enhance nursing cares.

Conclusion: Like previous research, we concluded that beside the negative impact of HSCT, it has little impact on the QoL patients. Patients submitted to HSCT treatment seems to have a QoL similar to the disease free group. HSCT is a treatment full of hope and it represents a second chance to live, and that it's something to get on.

### N1108

#### **What kind of problems you have to deal with in a BMT unit to implement an autologous transplantation in patients with autoimmune diseases**

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In our center from June 2005 to September 2007, 29 patients with autoimmune diseases have been treated with an autologous bone marrow transplantation: 20 multiple sclerosis (MS), 9 systemic sclerosis (SS). Patients affected by MS have been treated with BEAM and ATG conditioning, while patients with SS with Cyclofosamide and ATG. The total of the days observed is 683 on an average of 22 days of recovery. The needs of these patients requested a series of organizing and assistance interventions. The first step was training all the staff on these two diseases and, after this, we have started to evaluate the disability of the MS, before the recovery, with the EDDS scale, we have located a suitable room, we have removed architectonic barriers and we have supplied the ward with useful aids to manage the hypomobility of these patients (bed balance, anti decubitus mattress, hydraulic power lift). We have seen that MS during the period of recovery suffer a drop of their motor capacity with an average of days of complete dependence clearly superior to the transplanted patients with other pathologies (MS 5,7 gg vs SS 0 gg) and we have registered, especially in the aplasia phase, an elevated numbers of episodes of diarrhoea prolonged in time (4,5 gg with  $\geq 3$  evacuations a day); for all these reasons we have thought essential drawing up an early rehabilitative plan in collaboration with physiotherapists.

In SS chemotherapy usually improves their autonomy, but the pre-existent problems call for a careful monitoring of the compromised vital organs function (heart, lungs, kidney) and especially the continuous skin control, treating the typical skin lesions, present in 8 on 9 patients, and usually are many (until 9). These brought to a tight collaboration with the Rheumatology unit colleagues to draw up the treatment procedures and brought a daily heavy commitment of the dressings and the pain's management.

The burden of the assistance for both the patient's type it turned out to be superior to the one for patients undergoing an autologous transplantation for haematological disease and demanded an adjustment of the resources to respond to the request.

### N1109

#### **The importance of timely transplant for 2 brothers simultaneously diagnosed with X-linked adrenoleukodystrophy**

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X linked adrenoleukodystrophy (X-ALD) is an inherited disorder of very long chain fatty acid metabolism. The accumulation of these fatty acids is associated with cerebral demyelination, peripheral nerve abnormalities and adrenocortical and testicular insufficiency. Bone marrow transplant (BMT) performed early has been shown to reverse or stabilise abnormalities on cerebral MRI, making timely consideration of transplant important.

We present our experience in transplanting 2 brothers aged 9 and 7 yrs who were diagnosed simultaneously with X-ALD in 2006.

The patients' mother had symptoms of peripheral neuropathy and was diagnosed with the milder form of ALD. The maternal grandfather was diagnosed with a brain tumour at the same time. Genetic family screening then identified the boys and they were scanned by MRI. Children with MRI scores (Loes) of  $\geq 9$  have a very poor outcome compared with those with